IN THE UNITED STATES DISTRICT COURT
FOR THE EASTERN DISTRICT OF TEXAS
TYLER DIVISION

ALBERTO N., by his parents and next friends, Mr. and Mrs. N.; ALICE F. by her next friend, Ms. K; KEYAIRA R.-D., by her parent and next friend, Ms. D.; KAITLYN C., by her parent and next friend, Ms. C; AARON D., by his parent and next friend, Ms. D; ANDREW M., by his parent and next friend, Ms. M.; EVAN W., by his parents and next friends, Mr. and Mrs. W.; on behalf of themselves and others similarly situated,	§
Plaintiffs,	§
V.	§
DON A. GILBERT, in his official capacity as Commissioner of the Texas Health and Human Services Commission; WILLIAM R. ARCHER, III, M.D., in his official capacity as Commissioner of the Texas Department of Health; and ERIC M. BOST, in his official capacity as Commissioner of the Texas Department of Human Services,	§
Defendants.	§

NO. 6:99CV459

CLASS ACTION

COMPLAINT

I. INTRODUCTION

1. This lawsuit is filed on behalf of Medicaid beneficiaries under the age of twenty-one who have disabilities and chronic health conditions and who are unable to obtain

medically necessary in-home health care services. Plaintiffs are entitled to these medical services under the Early and Periodic Screening, Diagnosis, and Treatment ("EPSDT") program for Medicaid eligible individuals under the age of twenty-one.

2. Defendants, the Texas Health and Human Services Commission ("THHSC"), the Texas Department of Health ("TDH"), and the Texas Department of Human Services ("TDHS") (referred to collectively as "Texas Medicaid") have adopted policies and engaged in practices which have resulted in the systematic denial of in-home nursing services, medical equipment, and other support services for these children and young adults, in violation of the Medicaid Act, the Americans with Disabilities Act ("ADA"), and the Due Process Clause of the Fourteenth Amendment to the United States Constitution.

3. Plaintiffs seek declaratory and injunctive relief to end Defendants' unlawful policies and practices.

4. Plaintiffs sue on behalf of themselves and the class of all similarly situated Medicaid eligible individuals under the age of twenty-one who have been, or will be, unlawfully denied medically necessary in-home services from Texas Medicaid.

II. JURISDICTION AND VENUE

5. This Court has jurisdiction over this action pursuant to 28 U.S.C. §§ 1331 and 1343 (3) and (4).

6. This action is authorized by 42 U.S.C. § 12133 and by 28 U.S.C.§§ 2201 and 2202.

7. Venue is appropriate in the United States District Court for the Eastern District pursuant to 28 U.S.C. § 1391(b) because part of the events or omissions giving rise to these claims occurred in this District.

III. PARTIES

8. Plaintiff, Alberto N. is two-years-old and resides in McAllen, Hidalgo County, Texas. Alberto N. is a Medicaid beneficiary and is a qualified individual with a disability within the meaning of the ADA. 42 U.S.C. § 12131(2).

9. Plaintiff, Alice F. is two-years-old and resides in El Paso, El Paso County, Texas. Alice F. is a Medicaid beneficiary and is a qualified individual with a disability within the meaning of the ADA. 42 U.S.C. § 12131(2).

10. Plaintiff, Keyaira R.-D. is five-years-old and resides in Austin, Travis County, Texas. Keyaira R.-D. is a Medicaid beneficiary and is a qualified individual with a disability within the meaning of the ADA. 42 U.S.C. § 12131(2).

11. Plaintiff, Kaitlyn C. is nine-years-old and resides in Austin, Travis County, Texas. Kaitlyn C. is a Medicaid beneficiary and is a qualified individual with a disability within the meaning of the ADA. 42 U.S.C. § 12131(2).

12. Plaintiff, Aaron D. is ten-years-old and resides in Hallsville, Harrison County, Texas. Aaron D. is a Medicaid beneficiary and is a qualified individual with a disability within the meaning of the ADA. 42 U.S.C. § 12131(2).

13. Plaintiff, Andrew M. is eleven-years-old and lives in Tyler, Smith County, Texas. Andrew M. is a Medicaid beneficiary and is a qualified individual with a disability within the meaning of the ADA. 42 U.S.C. §12131(2).

14. Plaintiff, Evan W. is eleven-years-old and resides in Houston, Harris County, Texas. Evan W. is a Medicaid beneficiary and is a qualified individual with a disability within the meaning of the ADA. 42 U.S.C. § 12131(2).

15. Defendant, DON GILBERT, is the Commissioner of THHSC, the single state agency responsible for the administration of the Texas Medicaid program. In his capacity as Commissioner of the single state agency for Texas Medicaid, he is ultimately responsible for the operation of the Texas Medicaid program in accordance with the Medicaid Act, 42 U.S.C. § 1396 *et seq*. As Commissioner of the single state agency for Medicaid, Commissioner Gilbert may delegate the daily administration of Texas Medicaid to various state agencies. Don Gilbert is sued in his official capacity.

16. Defendant, WILLIAM R. ARCHER, III, M.D., is the Commissioner of the Texas Department of Health and has been delegated the administration of various parts of the Texas Medicaid program, including health care services for Medicaid beneficiaries under twenty-one years of age. Dr. Archer is sued in his official capacity.

17. Defendant, ERIC M. BOST, is the Commissioner of the Texas Department of Human Services and has been delegated the administration of various parts of the Texas Medicaid program, including the Primary Home Care Services benefit. Eric Bost is sued in his official capacity.

18. THHSC, TDH, and TDHS, the state agencies administered by Don Gilbert, Dr. Archer and Eric Bost, are responsible for the policies challenged by this lawsuit and are public entities within the meaning of the Americans with Disabilities Act.

IV. CLASS ACTION ALLEGATIONS

19. Named Plaintiffs bring this action on behalf of themselves, and pursuant to FED. R. CIV. P. 23(a) and 23(b), on behalf of a class defined as: all similarly situated Medicaid eligible individuals under the age of twenty-one in Texas who have been, or will be, unlawfully denied medically necessary services from Texas Medicaid.

20. The requirements of FED. R. CIV. P. 23 are met in that the class is so numerous that joining all members is impracticable. Approximately 1.4 million children and adolescents under the age of twenty-one in Texas are eligible for Medicaid services. According to TDH, approximately 19,500 Medicaid eligible children and youth require daily, ongoing, medical treatments and monitoring.

21. The requirements of FED. R. CIV. P. 23 are met in that all of the members of the class share common issues of law and fact. Plaintiffs are eligible for EPSDT services, but have been denied those services by Defendants. Defendants subject Plaintiffs and the class they represent to the same unlawful medical necessity determination process when they deny EPSDT services.

22. The requirements of FED. R. CIV. P. 23 are met in that the named Plaintiffs' claims that Defendants' failure to provide medical services in violation of the Medicaid Act,

the ADA, and the United States Constitution are typical of the claims of the class they represent.

23. The requirements of FED. R. CIV. P. 23 are met in that named Plaintiffs will fairly and adequately protect the interests of the class they represent.

24. The requirements of FED. R. CIV. P. 23 are met in that named Plaintiffs have no interest antagonistic to or in conflict with the interests of the class.

25. The requirements of FED. R. CIV. P. 23 are met in that Plaintiffs are represented by experienced counsel who will adequately represent the interests of the class. Counsel for Plaintiffs, Maureen O'Connell, Maryann Overath and Melissa Uram, are employed by Advocacy, Incorporated, the designated protection and advocacy agency that provides legal services to persons with disabilities.

26. Defendants have acted and refused to act and continue to do so on grounds generally applicable to the class the Plaintiffs represent, thereby rendering appropriate declaratory and injunctive relief for the class as a whole.

V. STATEMENT OF FACTS

The Medicaid Program

27. In 1965, Congress enacted Title XIX of the Social Security Act, 42 U.S.C. § 1396 *et seq.* ("the Medicaid Act"), establishing the Medicaid program, a voluntary, cooperative, federal-state program to provide necessary medical services to eligible beneficiaries. Texas elected to participate in the Medicaid program in 1967.

28. States that participate in the Medicaid program receive matching funds called federal financial participation ("FFP"). To receive FFP, states must adhere to the federal requirements found in the Medicaid Act and its implementing regulations. 42 U.S.C. § 1396a *et seq.*; 42 C.F.R. §§ 430 *et seq.*

29. Pursuant to these requirements, Texas has developed a state plan which identifies the broad categories of required and optional medical services which are part of the Texas Medicaid program. Under the provisions of the Act, Texas's Medicaid plan must provide the following required services: inpatient and outpatient hospital services; other laboratory and x-rays; nursing facility services; home health services (including durable medical equipment); early and periodic screening, diagnostic and treatment services ("EPSDT") for beneficiaries under age twenty-one; physicians services; nurse-midwife services; and certified pediatric and nurse practitioner services. 42 U.S.C. § 1396a; 42 C.F.R.§ 440.210.

30. In addition to the required services that must be included in the Medicaid state plan, Texas Medicaid can choose from a list of over thirty (30) optional services to include in its state plan. Examples of these optional services include: private duty nursing services; dental services; physical therapy; occupational therapy; services for individuals with speech, hearing and language disorders; case management services; and personal care services. 42 U.S.C. § 1396(d)(a); 42 C.F.R. § 440. *et seq.*

31. To further comply with the Medicaid Act, Texas Medicaid must set reasonable standards in the operation of its program. 42 U.S.C. § 1396a(a)(17).

32. Moreover, each service within the Medicaid state plan must be sufficient in amount, duration, and scope to reasonably achieve its purpose and services may not be arbitrarily denied or reduced in amount, duration, and scope because of the diagnosis, type of illness, or condition of an eligible beneficiary. 42 C.F.R. §§ 440.230(b) and (c).

33. Texas Medicaid must also inform Medicaid beneficiaries of the available health care and treatment available under the program. 42 U.S.C. § 1396(a)(43)(A).

Medicaid Services for Beneficiaries under the Age of Twenty-one

34. In 1990, the Medicaid Act was amended to expand the scope of services available under the EPSDT benefit, a required category of service for beneficiaries under the age of twenty-one. This amendment requires Texas Medicaid to provide "such other necessary health care, diagnostic services, treatment, . . . to correct or ameliorate defects and physical and mental illnesses and conditions . . ." 42 U.S.C. § 1396d(r)(5).

35. Under this expanded EPSDT benefit, called Texas Health Steps Comprehensive Care Program ("CCP"), Texas Medicaid is required to provide all optional and required categories of service under the Medicaid Act to beneficiaries under the age of twenty-one when such treatment or service is found to be medically necessary. 42 U.S.C. §§ 1396a(a)(10)(A), 1396d(r)(5).

36. Texas Medicaid describes CCP services as the set of services mandated by federal law to provide all medically necessary, appropriate, and federally allowable services to children, including those services that are not covered under the state's Medicaid plan for Medicaid beneficiaries 21 years-of-age or older.

37. Texas Medicaid defines the term "medical necessity," in relevant part, as "the need for medical services in an amount and frequency sufficient, according to accepted standards of medical practice, to preserve health and life and to prevent future impairment." 25 TAC § 43.25.

38. To obtain CCP services, the Medicaid beneficiary's treating physician must prescribe the service and attest to the beneficiary's medical necessity for the service.

39. Medicaid beneficiaries obtain CCP services, such as private duty nursing, speech therapy, occupational therapy, physical therapy and medical equipment, by submitting a request for prior authorization to Texas Medicaid, that includes the treating physician's statement that the service is medically necessary for the beneficiary.

40. Texas Medicaid contracts with a private health insuring organization, National Heritage Insurance Company ("NHIC") to administer part of the Medicaid program, including making determinations as to whether Medicaid applicants or participants meet the medical necessity criteria for Medicaid services.

41. Texas Medicaid is responsible for all Medicaid coverage and medical necessity determinations made by NHIC.

42. These determinations must be made in a timely manner as EPSDT treatment services must be provided in a timely fashion, with an outside limit of six (6) months from the date of the request. 42 C.F.R. § 441.56(e).

43. Texas Medicaid must also "make available a variety of individual and group providers qualified and willing to provide EPSDT services." 42 C.F.R. § 441.61(b).

The Texas Medicaid Home and Community-Based Waiver Program for Medicaid Beneficiaries Under the Age of 21

44. In addition to the services available through the EPSDT benefit, approximately 816 Medicaid beneficiaries receive supplemental health services through the Medically Dependent Children's Program ("MDCP"). This program is a Medicaid Home and Community-Based waiver program designed to provide home and community-based services to Medicaid beneficiaries under age twenty-one as an alternative to institutionalization. 42 U.S.C. § 1396n(c)(2), 25 TAC § 34.1 *et. seq.*

45. In order to operate a Home and Community-Based waiver consistent with the requirements of the Medicaid Act, 42 U.S.C. § 1396n(c)(2)(D), Texas Medicaid must assure that the average per capita expenditure for waiver participants does not exceed 100 percent of the average per capita expenditure that the state estimates would be made for expenditures under the state plan for such individuals if the waiver was not in effect.

46. To be eligible for MDCP, the beneficiary must meet the medical necessity criteria for nursing facility care.

47. Each MDCP participant has an Individual Plan of Care that describes the array of in-home and community services to be provided to the participant.

48. The cost of the Individual Plan of Care cannot exceed the cost allowance assigned to the participant.

49. The cost allowance is the maximum dollar amount available for reimbursement for an MDCP participant's approved waiver services. The cost allowance is equal to

63 percent of the annual reimbursement rate that Texas Medicaid would pay for skilled nursing facility care as of September 1, 1996.

50. Texas Medicaid determines the reimbursement rate for skilled nursing facility care by computing the participant's Texas Index for Level of Effort ("TILE") designation. The TILE designation is based on the intensity of the care needs of individuals in Texas nursing facilities.

51. Texas Medicaid will pay 100 percent of the TILE reimbursement rate for services provided to a Medicaid beneficiary in a nursing facility; however, it will only pay 63 percent of the TILE rate for services provided to the beneficiary through the MDCP program in the home and community.

52. Prior to 1997, the array of services available under MDCP included private duty nursing services. However, in September 1997, Texas Medicaid eliminated private duty nursing services as benefit of MDCP because this service must be made available to all Medicaid beneficiaries through the CCP and waiver services are designed to supplement, not replace, state plan services.

Due Process Protections for Medicaid Beneficiaries

53. The Medicaid Act and federal regulations promulgated pursuant to the Medicaid Act require Texas Medicaid to inform Medicaid beneficiaries in writing of their right to request a fair hearing if their claim for benefits is reduced, denied, terminated or not acted upon with reasonable promptness. 42 U.S.C. § 1396a(a)(3); 42 C.F.R. § 431.200 *et seq*.

54. Notice of a reduction, denial or termination of benefits or of a claim that is not acted upon with reasonable promptness must include: a statement of what action Texas Medicaid intends to take; the reasons for the intended action; the specific regulations that support, or the change in Federal or State law that require, the action; an explanation of the individual's right to request an evidentiary hearing, if one is available, or a State agency hearing; in cases of an action based on a change in law, the circumstances under which a hearing will be granted; and an explanation of the circumstances under which Medicaid is continued if a hearing is requested. 42 C.F.R. § 431.210.

55. Texas Medicaid must mail the notice at least ten days before the date of action. 42 C.F.R. § 431.211.

Texas Medicaid's Failure to Comply with the Medicaid Act

56. Although Texas Medicaid acknowledges that it must provide all medically necessary services to Medicaid beneficiaries under the age of twenty-one, Defendants, through NHIC, routinely deny, terminate and reduce in-home nursing, personal assistance services, and medical equipment to Medicaid beneficiaries under the age of twenty-one in disregard of the opinion of the treating professionals.

57. Plaintiffs, as described below, have all submitted requests for prior authorization for in-home Medicaid services. The requests included statements by Plaintiffs' treating physicians that the services are medically necessary. The need for medical services met Texas Medicaid's definition of medical necessity, in that the services were prescribed

"in an amount and frequency sufficient, according to accepted standards of medical practice, to preserve health and life and to prevent future impairment."

58. Texas Medicaid denied these requests for in-home Medicaid services without evaluation of Plaintiffs and despite the opinions of the treating physicians that the services are medically necessary.

59. Not only does Texas Medicaid fail to defer to the treating physician's opinion regarding medical necessity, it fails to use its own definition of medical necessity when over-ruling the treating physician and, instead, makes arbitrary determinations with no reference to medical standards.

60. Texas Medicaid reduces and terminates medical services being provided to Medicaid beneficiaries even though the beneficiary's medical condition has not changed and, therefore, no reduction or termination of services is warranted.

61. Additionally, Texas Medicaid denied requests by MDCP participants for CCP in-home nursing services despite previous assurances by MDCP administrators that MDCP participants would be able to access private duty nursing services through CCP once these services were eliminated from the array of MDCP benefits.

62. After making decisions to deny, reduce, or terminate a service, Texas Medicaid frequently fails to provide notice to the Medicaid beneficiary regarding the denial, reduction, or termination of the service and the beneficiary's right to request a fair hearing to challenge the denial, reduction, or termination of the service.

63. Even when Texas Medicaid provides notice to the Medicaid beneficiary, the notice fails to state the reasons for the intended action, the specific regulations that support, or the change in Federal or State law that required the action, and fails to provide an explanation of the circumstances under which Medicaid is continued if a hearing is requested.

64. These notices often state only that the "documentation does not support the medical necessity" for the service. The notice fails to provide any explanation or reason as to why the documentation provided by the treating physician fails to support the medical necessity for the service; nor does it provide the criteria upon which the determination was made.

65. Without information regarding the basis upon which Texas Medicaid has denied, terminated, or reduced the requested service, Medicaid beneficiaries have no opportunity to successfully appeal the denial, termination, or reduction.

66. Texas Medicaid fails to provide notice to beneficiaries when it determines that a requested benefit is not covered within the Medicaid program. It sometimes provides notice to the Medicaid provider; however, even then, the notice only states "not covered," and provides no other information regarding this determination.

67. Texas Medicaid does not provide beneficiaries an opportunity to request a fair hearing to challenge a determination that a benefit is not covered within the Medicaid program.

68. In sum, Texas Medicaid denies, reduces and terminates medical services, without evaluation of the beneficiaries, consultation with their physicians, and in direct contradiction to the recommendations of the beneficiaries' treating physicians, the beneficiaries' medical status, and its own definition of medical necessity. It subsequently fails to provide the beneficiaries with proper notice of the denial, reduction or termination of services and fails to provide beneficiaries with the opportunity to request a fair hearing to challenge the denial, reduction, or termination of services.

The Named Plaintiffs

Alberto N.

69. Alberto N. was born on January 21, 1997, and lives with his mother, father and four young siblings in McAllen, Texas. The Ns. left their home and family in Laredo, Texas, to move to McAllen in order to obtain medical services for Alberto.

70. Alberto was diagnosed with Spinal Muscular Atrophy-Werdnig Hoffmann type ("SMA"), at the age of four months after experiencing repeated respiratory failure. SMA is a neurological disease that causes rapid and severe degeneration of the cells in the nervous system. These cells are responsible for sending signals to the muscles of the body, including the muscles used to breath.

71. As a result of the degeneration of these cells, Alberto has paralysis and cannot breath independently. Instead, Alberto's breathing is assisted with a ventilator. The ventilator "breathes" for Alberto through a tube that has been placed in his windpipe, called a tracheotomy.

72. Alberto spent most of the first five months of his life in the hospital. He was discharged from the hospital in June 1997, and went home with the support of the ventilator.

73. Alberto requires the use of the ventilator twenty-four hours per day. Alberto's tracheotomy tube must be suctioned every five-to-ten minutes so that he can continue breathing. Because Alberto must be monitored and suctioned twenty-four hours per day, he can not be left unattended by trained professionals.

74. As a result of the SMA, Alberto has many other medical needs including the need to be fed through a gastrostomy tube ("g-tube") in his stomach. He must be fed through the g-tube fifteen times per day.

75. Alberto requires a number of medications that are administered through injection, the g-tube or through a nebulizer, as well as medications applied to his skin to address skin breakdown caused by his inability to change positions independently.

76. Alberto's physician, Humberto Hidalgo, M.D., board certified pediatric pulmonologist, and the nursing agency that provides Alberto's nursing services, MCH Services Pediatric Nursing Specialists, have written detailed plans of medical treatment for Alberto, that describe Alberto's need for the following skilled care services: oral, nasal and tracheotomy suctioning every five-to-ten minutes; hyperventilating Alberto, if necessary, after suctioning; assessment and monitoring of cardiopulmonary status; assessment and evaluation of lung sounds and breathing patterns; provision of oxygen for respiratory distress; assessment and monitoring of oxygen levels using a pulse oximeter; monitoring ventilator settings; g-tube feeding; administration of medication; assessment for signs and

symptoms of dehydration; monitoring of bowel movements; assessment, monitoring and treatment of skin breakdown; positioning Alberto to diminish skin breakdown; assessment and monitoring of neurological status; hanging the tracheotomy ties daily; and, changing the tracheotomy tube as needed, but at least every two weeks. The plan also requires that Alberto be provided assistance with all activities of daily living including: bathing, diapering, oral hygiene, and gentle range of motion exercises.

77. At the age of five-months, Alberto was discharged from the hospital and Texas Medicaid provided him with 24 hours per day of nursing services for fifteen (15) days. Texas Medicaid then reduced the number of nursing services hours to 22 hours per day and provided those services for ten (10) weeks. Subsequently, Texas Medicaid has reduced the nursing services hours by one to two hours, every three months. None of these reductions have been based upon the professional opinion of Alberto's treating physician, Dr. Hidalgo, or the nursing agency, MCH.

78. On March 5, 1998, Dr. Hidalgo submitted a request to Texas Medicaid for prior authorization of 18 hours per day of nursing services for Alberto. Texas Medicaid, through NHIC, denied the request for 18 hours per day but authorized the provision of 16 hours of nursing services per day for the period of March 3, 1998, through April 26, 1998, 15 hours of nursing services per day for the period April 27, 1998, through May 26, 1998, and 14 hours of nursing services per day for the period May 27, 1998, through June 26, 1998.

79. Texas Medicaid reduced the nursing services, without evaluation of Alberto, consultation with his physician, and in direct contradiction to the recommendations of Alberto's treating physician and nurses.

80. Ms. N. requested a fair hearing to appeal the reduction and a hearing was held on May 14, 1998.

81. The TDH hearing examiner sustained Texas Medicaid's decision to reduce the nursing services. The decision does not defer to, or even mention, the opinion of Alberto's treating physician. Despite the plan of treatment confirming Alberto's medical need for nursing services, the hearing examiner found that Alberto has some skilled nursing needs but that most of his needs are custodial or respite.

82. On August 31, 1998, MCH Services received notice from NHIC that Texas Medicaid denied Dr. Hidalgo's prior authorization request to provide nursing services to Alberto for 16 hours per day from August 17, 1998 to October 10, 1998. The denial stated that the "doc does not support medical necessity."

83. Ms. N. did not receive notice of the denial until after September 23, 1998. The notice stated that the "medical information received does not support the number of hours being requested." It failed to provide any other information about the basis for the denial of nursing services, it did not describe the federal regulations that support the denial of services and it failed to provide an explanation of the circumstances under which the services are continued if a hearing is requested.

84. Texas Medicaid approved 14 hours per day of nursing services and informed the nursing agency, during telephone conversations about the prior authorization request, that it planned to reduce the 14 hours per day to ten hours per day beginning September 16, 1998.

85. Texas Medicaid, through NHIC, denied the request to provide 16 hours per day of nursing services, without evaluation of Alberto, consultation with his physicians, and in direct contradiction to the recommendations of Alberto's treating physician and nurses.

86. Both Dr. Hidalgo and MCH Services submitted additional letters to NHIC describing Alberto's medical necessity for 18-20 hours of nursing services per day, not to be reduced below 16 hours.

87. Texas Medicaid has refused to provide the 18-20 hours per day of nursing services prescribed by Dr. Hidalgo. Alberto currently receives 14 hours per day of nursing service and, upon information and belief, Texas Medicaid will continue to reduce those hours despite the treating physician's opinion regarding Alberto's medical need for nursing services.

88. Nursing services are provided to Alberto during the hours of 4 p.m. to 6 a.m. At 6 a.m., Ms. N. assumes the responsibility for providing Alberto with all of his nursing services, although Ms. N. is not a nurse and has had no formal medical training.

89. In order to provide Alberto with the medical support services he needs, including suctioning, Ms. N. cannot leave his bedside for more than several minutes at a time.

90. Ms. N. has four other children: two sons, ages two and four, and two daughters, ages eight and ten. The tremendous amount of medical care that she must provide to Alberto impacts her ability to care for her other children.

91. Ms. N. has also applied for Primary Home Care Services for Alberto. Primary Home Care Services is a Medicaid benefit that provides personal assistance services, and is administered by the Texas Department of Human Services ("TDHS").

92. In June 1998, TDHS denied the request for primary home care services. The notice stated that the services were "denied due to lack of functional need." No other information describing the basis for the denial was provided in the notice.

Alice F.

93. Alice F. was born on April 12, 1997. Shortly after her birth, she was placed in the permanent managing conservatorship of the Texas Department of Protective and Regulatory Services. Placement with the Ks, a foster family in El Paso, Texas, was authorized on August 1, 1997, and since that time she has remained in their home.

94. Alice was born prematurely and was immediately diagnosed with Trisomy 18, a chromosomal condition associated with the presence of an extra number 18 chromosome. The extra chromosome causes organ malformations and in Alice's case, has resulted in a congenital heart defect, a gastro-intestinal disorder, developmental delay and partial blindness.

95. Alice's heart defect, Tetralogy of Fallot, is the most disabling aspect of her Trisomy 18. The condition has caused a hole in the wall separating the right and left

ventricles, a narrowing of the pulmonary valve, a displaced aorta, and a thickening of the left ventricle wall. Because of these impairments, blood flow to the lungs is obstructed and insufficiently oxygenated blood is pumped through her body. Oxygen, therefore, must be administered to Alice on a twenty-four hour basis and monitored closely throughout that time. As a result, Alice is at risk of sudden death.

96. Trisomy 18 also affects Alice's esophagus. She has been diagnosed with Esophageal Atresia which is a narrowing or obstruction of the esophagus. This condition requires that she be fed through a gastrostomy tube ("g-tube") in her stomach. The feeding process must be initiated every four hours and each feeding lasts approximately one hour. Feedings are often difficult because Alice's esophagus causes frequent vomiting. Additionally, all medications must be administered through the g-tube.

97. Alice's heart condition also contributes to sleep apnea, an abrupt cessation of breathing during sleep. As a result, she has very irregular sleeping patterns and never sleeps longer than two hours at a time. Oxygen must be constantly monitored while Alice is both asleep and awake by checking for cyanosis, a blueing of the skin due to decreased oxygen levels in the blood. When cyanotic spells occur, oxygen must be increased to resupply the blood with oxygen. However, a severe cessation of breathing is a persistent possibility and Alice's caregiver must be trained in infant CPR to appropriately respond to this threat.

98. Alice has been in the care of two physicians since her initial release from the hospital, Dr. John Guggeddah and, currently, Dr. Jagdish Patel of the Pediatric Health Center in El Paso, Texas. Two nursing agencies have provided her skilled nursing services,

Visiting Nurse Association of El Paso ("VNA") and, currently, Pasos Home Health. These medical professionals have developed a plan of care which itemizes Alice's specific care needs.

99. Alice's current daily skilled nursing care needs are listed in that plan as follows: assessment of cardiovascular system by monitoring heart sounds, peripheral circulation, and pulse; assessment of respiratory status by listening to lung sounds and analyzing cough/sputem; assessment of gastrointestinal status by listening to bowel sounds and monitoring nutrition and elimination; monitoring skin breakdown; administration of medication every four, six, and twelve hours; assessment of g-tube placement and signs or symptoms of complications; assessment of hydration status; assessment of home safety measures; assessment of Alice's comfort and pain status; cleaning of g-tube site; administration of inhalation therapy; performance of chest physiotherapy ("CPT") every four hours; administration of saline drops to nose; provision of verbal and tactile stimulation throughout shift; instruction to caregiver on disease process, treatment, management, and appropriate interventions.

100. Upon Alice's placement in her foster home, Texas Medicaid provided Alice with eight hours per day (56 hours per week) of skilled nursing services to administer Alice's plan of care. The remainder of the day and evening Alice was cared for by her foster mother, Ms. K. Ms. K. is not a nurse but has had some medical training in Mexico.

101. Texas Medicaid continued to provide 56 hours of nursing services per week until October 1998. At that time, Alice's nursing services provider changed from VNA to

Pasos Home Health. Pasos Home Health sought prior authorization to provide 56 hours per week of nursing services to Alice for the period of October 16, 1998 through December 16, 1998. Pasos Home Health received notice that prior authorization for 56 hours a week of private duty nursing was denied.

102. Initially, Texas Medicaid, through NHIC, denied the request because it mistakenly understood that VNA was authorized to provide services and that any additional authorizations would result in duplication of Medicaid services. Pasos Home Heath provided Texas Medicaid with documentation indicating that it is the sole home health agency caring for Alice but Texas Medicaid denied the request for prior authorization on December 3, 1998. Ms. K. did not receive a copy of this denial.

103. Pasos Home Health secured additional documentation that Alice's foster family and caregiver wished to change providers from VNA to Pasos Home Health. They submitted this letter along with the previously submitted paperwork requesting prior authorization on December 3, 1998. The application was denied for the second time. This denial, dated December 9,1999, stated, "Documentation submitted does not support medical necessity for hourly nursing. Caregiver is trained. Documentation does not indicate client is unstable. CCP does not authorize hours for respite care." Mrs. K. did not receive a copy of this denial.

104. Texas Medicaid, through NHIC, denied the nursing services, without evaluation of Alice, consultation with her physicians, and in direct contradiction to the recommendations of Alice's treating physician and nurses.

105. Throughout this time period, Pasos Home Health continued to provide Alice with 56 hours of nursing services per week and submitted an appeal of the denial, seeking payment for the services. Texas Medicaid responded to the Pasos Home Health's appeal on March 29, 1999, by authorizing payment for skilled nursing services for 40 hours per week from October 16, 1998 through November 15, 1998, and 20 hours per week from November 16, 1998 through December 15, 1998. After that date, Alice was to be discharged from all services.

106. The approval for these hours, however, has never resulted in payment to Pasos Home Health for services rendered from October through December. Approval for these hours was authorized on March 29, 1999, and, as a result, Texas Medicaid refuses to process the payment claims submitted by Pasos Home Health because they were submitted after the 95-day billing period.

107. On the same date that Pasos Home Heath submitted its prior authorization application to Texas Medicaid for the period of October 16, 1999 through December 15, 1999, it submitted two additional requests for prior authorization of Alice's care. These requests, for the periods of December 16, 1999 through February 15, 1999, and February 16, 1999 through April 15, 1999, resulted in March 29, 1999, denials by Texas Medicaid. Each denial stated, "Documentation does not support medical necessity for hourly nursing." Mrs. K. did not receive copies of these denials.

108. On April 27, 1999, the billing agent at Pasos Home Health was called by a representative of Texas Medicaid who urged her to resubmit the requests for prior

authorization for the period of February 16, 1999 through April 15, 1999. Pasos Home Health followed this suggestion and submitted a request for 56 hours per week of skilled nursing services for Alice on April 27, 1999, April 30, 1999, and May 4, 1999. The requests included an additional letter from Alice's caseworker at the Texas Department of Protective and Regulatory Services, which stressed the need for approval of a full 56 hours of skilled nursing, as well as a court order from an El Paso County District Court.

109. Citing omissions in the application paperwork, Texas Medicaid denied the first two requests for prior authorization. The third application resulted in approval for the requested 56 hours on May 27, 1999. However, approval for 56 hours per week of nursing services was granted only for the time period February 16, 1999 through March 15, 1999. For the period of March 16, 1999 through March 29, 1999, Texas Medicaid approved only 50 hours of skilled nursing services; for the period of March 30, 1999 through April 12, 1999, Texas Medicaid approved 45 hours, and for the following two days, April 13, 1999 through April 15, 1999, Texas Medicaid approved only 40 hours of skilled nursing.

110. After this limited authorization was received, Pasos Home Health continued to file requests for prior authorization on Alice's behalf for 56 hours per week of skilled nursing services. A request was submitted on June 1, 1999, for services between April 16, 1999 and June 15, 1999, but only 40 hours of skilled nursing per week were approved. The denial, received on June 2, 1999, stated that "Documentation submitted does not support the number of hours you requested." Once again, Mrs. K did not receive a copy of the denial. Pasos is currently appealing this decision.

111. The most recent request for prior authorization for services for the period June 16, 1999 to August 15, 1999, was submitted to Texas Medicaid by Pasos Home Health on July 8, 1999.

112. Although 56 hours per week of skilled nursing services were requested, Texas Medicaid again approved only 40 hours per week. The notice was issued on July 8, 1999, and it stated that the documentation did not support the requested number of hours. Mrs. K. did not receive a copy of this notice.

113. Alice's physician has alerted Texas Medicaid that Alice requires 24-hour care and that her foster mother is ill-equipped to provide it on her own, by including an additional letter of need, dated April 26, 1999, with her plan of care.

114. Alice's foster mother does not believe that she can personally care for Alice's needs around-the-clock and fears that she will not be able to continue with Alice's placement in her home if she is expected to do so.

115. The threat to Alice's current foster placement was recognized by the El Paso District County Court. On October 1, 1998, Judge Patricia Macias issued an order approving a permanent foster care arrangement with Alice and her current foster family. To ensure the success of that arrangement, an additional court order was issued that Alice "be provided with continuous and constant home nursing care for no less than 8 hours a day." Since Medicaid refused to pay for this service, the Child Welfare Board was petitioned and agreed to pay the nursing expenses incurred during that period. Skilled nursing continues to be

provided to Alice for 56 hours each week as a result of the court order, but Pasos Home Health has been reimbursed for only a fraction of these services by Medicaid.

116. Without the additional medically necessary nursing services she requires and an assurance that Texas Medicaid will provide coverage, Alice is at risk of losing her foster care placement and being placed in an institution.

Keyaira R.-D.

117. Keyaira R.-D. is five-years-old and lives with her grandmother, Rita D., in Austin, Texas. Ms. D. is managing conservator for Keyaira.

118. Keyaira is a Medicaid beneficiary who has participated in the Medicaid program since 1994.

119. When Keyaira was four-months-old, she sustained a closed head injury, resulting in a fractured skull and a subdural hemorrhage that lead to cerebral edema. As a result, Keyaira is unable to speak and has quadriplegia, a seizure disorder, a vision impairment, history of trachia malaysia causing difficulty swallowing, global developmental delay and gastroesophageal reflux

120. Because of the quadriplegia, Keyaira uses a wheelchair for mobility. She has increased tone in her upper extremities, impacting her range of motion.

121. In order to decrease the likelihood of atrophy to her muscles and to increase her strength, one of Keyaira's treating physicians, Ezam Ghodsi, M.D., prescribed the use of a Mayatek muscle stimulator.

122. The Mayatek muscle stimulator is a piece of durable medical equipment that is used to increase blood flow to the muscles through electric stimulation.

123. Durable medical equipment is a benefit of the Texas Medicaid program.

124. In July 1998, Dr. Ghodsi submitted a request to Texas Medicaid that it fund the cost of the Mayatek muscle stimulator. On July 14, 1998, Texas Medicaid, through NHIC, denied the request.

125. Texas Medicaid did not send notice of this denial to Ms. D.

126. Upon information and belief, Ms. D. did not receive a denial notice because Texas Medicaid never provides notice to beneficiaries when it determines that a service is not a covered benefit of the Medicaid program.

127. Instead, the medical equipment provider, D&L Medical Products, Inc, received a copy of the application it had sent in support of the request for the muscle stimulator and written across the application were the words, "not a benefit of the home health program." This "notice" failed to provide any other information about the basis for the denial of Medicaid coverage of the Mayatek muscle stimulator.

128. Texas Medicaid has also terminated all of Keyaira's nursing services.

129. Keyaira began receiving nursing services in 1994, subsequent to sustaining the closed head injury.

130. Keyaira requires assistance with all activities of daily living, including assistance with eating. She must be monitored closely because of the risk of aspiration associated with reflux. She also requires clinical observation because of her seizure disorder.

She must have a number of medications administered, including nebulizer treatments. She is unable to move independently and must be positioned properly to avoid skin breakdown.

131. For two weeks following her discharge from a rehabilitation hospital in November 1994, she received 84 hours of nursing services per week. Then, until November 1995, she received 56 hours of nursing services per week.

132. From November 1995 until November 1997, she received 51 hours of nursing services per week.

133. From November 1997 until February 1998, she received 40 hours of nursing services per week.

134. In January 1998, Keyaira's primary care physician, Joel Blumberg, M.D., and the nursing agency providing nursing services, Seton Home Health Care, submitted a prior authorization request to Texas Medicaid seeking authorization to continue providing Keyaira with 40 hours of nursing services per week, to be provided from February 1998 through May 1998. Texas Medicaid, through NHIC, denied the request for prior authorization for 40 hours of nursing services per week and, instead, approved 30 hours per week to be provided until the end of February 1998, and 20 hours per week to be provided during March 1998.

135. Texas Medicaid, through NHIC, terminated all of Keyaira's nursing services as of March 31, 1998, without evaluation of Keyaira, consultation with her physicians, and in direct contradiction to the recommendations of Keyaira's treating physician and nurses.

136. Upon information and belief, Ms. D. did not receive notice of the reduction and termination of nursing services.

137. Seton Home Health Care received notice of the reduction and termination of the nursing services; however, the notice failed to provide any other information about the basis for the termination of nursing services, and it did not describe the federal regulations that support the termination of services.

138. Seton Home Health Care and Dr. Blumberg submitted letters in March 1998 requesting that Texas Medicaid reconsider its decision to reduce and terminate Keyaira's nursing services. Texas Medicaid did not respond to this request.

139. Ms. D. requested a fair hearing to appeal the decision to reduce and terminate the nursing services.

140. A fair hearing was held by telephone on April 2, 1998. The TDH hearing examiner, Marc Allen Connelly, issued a decision on June 9, 1998, sustaining Texas Medicaid's decision to reduce and terminate the nursing services.

141. Despite the plan of care and the letters submitted by Dr. Blumberg and Seton Home Health Care to Texas Medicaid, confirming Keyaira's medical need for nursing services, Mr. Connelly found that Keyaira has "no skilled nursing needs" and that "no medical necessity or medical documentation was submitted to support providing private duty nursing."

142. Keyaira continues to require 40 hours of nursing services per week. Without this assistance, Ms. D. had to take a leave of absence from her job to provide care for Keyaira. When she returned to work in August 1998, she had to reduce her work schedule. Ms. D. is not a nurse nor has she had formal medical training.

143. During the summer 1998, Ms. D. contacted TDHS seeking assistance for Keyaira. Ms. D. inquired about personal assistance services from the Primary Home Care Program. Primary Home Care Services is a Medicaid benefit that provides personal attendant care services and is operated by TDHS. Ms. D. was told that Keyaira does not qualify for those services.

144. In May 1999, Ms. D. once again tried to obtain personal assistance services through the Primary Home Care Program, for Keyaira. Initially, she was informed that the program does not serve children; however, the program later agreed to do an assessment of Keyaira.

145. A representative from the Primary Home Care Program assessed Keyaira and determined that while she can obtain approximately 20 hours per week of personal assistance services, the services will only be provided during those hours that Ms. D. is at home with Keyaira. Additionally the personal assistant cannot provide any of the medical support services that Keyaira needs.

Kaitlyn C.

146. Kaitlyn is nine-years-old and lives with her mother, Ms. C. Kaitlyn became eligible for Medicaid in 1992 when she began participating in the MDCP waiver program. As a Medicaid beneficiary, Kaitlyn is also entitled to CCP services.

147. Kaitlyn has a diagnosis of chorea athetoid cerebral palsy and static encephalopathy, a brain disorder of unknown cause. Kaitlyn has quadriplegia, cortical blindness, a seizure disorder, global developmental delay, scoliosis, and she is non-verbal.

Kaitlyn uses a wheelchair for mobility, a voice output device for communication, and receives food and drink through a gastrostomy tube ("g-tube").

148. Kaitlyn's seizures are atypical and are not controlled by medication. Kaitlyn's seizure disorder produces at least two different types of seizures. For seven-to-ten days each month, Kaitlyn experiences an episode of inconsolable crying, uncontrollable thrashing, and screaming lasting 24 hours per day. During this time period, unless medicated with a sedative, Kaitlyn sleeps for only two-to-three minutes at a time. Even when sedated, Kaitlyn sleeps for only three-to-four hours at a time. She sometimes will have seizures during this time which have been unresponsive to anti-convulsants. Kaitlyn requires constant monitoring so that she doesn't injure herself and so that she can be suctioned in order to avoid choking on saliva. She sometimes also requires chest physiotherapy ("CPT").

149. One to two weeks prior to this time period, Kaitlyn has other types of seizures. These seizures occur erratically and cause excessive saliva, choking, uncontrolled laughing and breathing difficulty. During these seizures Kaitlyn frequently has to be suctioned and sometimes requires CPT.

150. Kaitlyn requires assistance with all of her care needs: positioning, bathing, feeding, toileting, and skin care to avoid skin breakdown.

151. In order to maintain Kaitlyn's health and safety, her treating physician, Dr. Janet Mitchell, M.D., has prescribed approximately 40 hours of nursing services per week for Kaitlyn since 1992.

152. Beginning in 1992 and prior to October 1997, Kaitlyn received nursing services from both MDCP and CCP. MDCP provided 24 hours per week of nursing services and CCP provided 12 hours per week of nursing services, totaling 36 hours per week of nursing services.

153. Kaitlyn received the following nursing services: g-tube feeding, oral and nasal suctioning, medicine administration, incontinent care, skin care, seizure precautions, assessment of neurological status, assessment of vital signs, pain management, emergency response to respiratory problems associated with the seizure activity and CPT.

154. During the heaviest periods of seizure activity, uncontrollable thrashing and screaming, Kaitlyn received these services eight-to-ten hours per day.

155. In August 1997, Kaitlyn's MDCP case manager informed Kaitlyn's mother that the MDCP program was changing its scope of services and would no longer provide nursing services as it had done in the past. The case manager informed Ms. C. that Kaitlyn would have to access all of her nursing services through CCP, as of February 1998.

156. In September 1997, pursuant to the plan of care developed and signed by Dr. Mitchell, the home health agency that serves Kaitlyn, Seton Home Care, submitted a request for prior authorization to Texas Medicaid for the 12 hours per week of CCP nursing services that it had been routinely providing to Kaitlyn since 1992. The requested prior authorization period encompassed October 1, 1997 to December 31, 1997.

157. Texas Medicaid, through NHIC, denied this request; however, Ms. C. did not receive notice of the denial until November 1997.

158. The notice stated only that the "documentation does not support medical necessity." It failed to provide any other information about the basis for the termination of nursing services, it did not describe the federal regulations that support the termination of services and it failed to provide an explanation of the circumstances under which the services are continued if a hearing is requested.

159. Texas Medicaid, through NHIC, denied the nursing services, without evaluation of Kaitlyn, consultation with her physicians, and in direct contradiction to the recommendations of Kaitlyn's treating physician and nurses.

160. The denial of services directly contradicted the statements by the MDCP casemanager that not only could Kaitlyn receive 12 hours per week of nursing services she had always received from CCP but that she would also be able to access, through CCP, the nursing services hours that were to be discontinued under MDCP.

161. Subsequent to the denial, Ms. C. provided Texas Medicaid with additional medical documentation from Kaitlyn's physician and the home health care agency, supporting Kaitlyn's medical need for the nursing services.

162. Texas Medicaid continued to deny the request for 12 hours per week of nursing services; however, it approved 20 hours of nursing services per month, to be provided on an "as needed" basis, through CCP.

163. In March 1998, the home health care agency submitted another request for prior authorization to Texas Medicaid seeking authorization to provide 30 hours per week of nursing services to Kaitlyn, through CCP. This request was denied; however, 20 hours

per month (approximately 4½ hours per week) of nursing services was approved, on an "as needed" basis.

164. In August 1998, MDCP reduced Kaitlyn's nursing service hours from 26 hours per week to 10 hours per week.

165. In June 1999, Texas Medicaid, through NHIC, terminated the 20 hours per month of nursing services being provided through CCP, even though Kaitlyn's medical needs have not changed and her treating physician continues to recommend that she receive 40 hours per week of nursing services.

166. The notice stated that the "medical information received does not support the number of hours being requested." It failed to provide any other information about the basis for the termination of nursing services; the federal regulations cited were incorrect and do not support the termination of services; and the notice failed to provide an explanation of the circumstances under which the services are continued if a hearing is requested.

167. Currently, Kaitlyn receives 10 hours of nursing services per week from MDCP and no nursing services from CCP. According to Kaitlyn's treating physician and nurses, Kaitlyn has a medical need for 40 hours per week of nursing services. Therefore, she is currently unable to access 30 hours of nursing services that she needs each week.

168. Ms. C. is not a nurse nor has she had formal medical training.

169. In order to provide Kaitlyn with care, Ms. C. does not sleep during the heaviest periods of seizure activity and she has periodically been forced to reduce her hours at work.

170. Administrators of MDCP and CCP have suggested that Ms. C. obtain non-skilled care for Kaitlyn through the Primary Home Care Services program. Primary Home Care Services is a Medicaid benefit that provides personal attendant care services and is operated by Texas Department of Human Services ("TDHS").

171. Ms. C. applied for Primary Home Care Services in February 1998, and TDHS denied the request. Ms. C. was told that Kaitlyn's medical needs required skilled care and that the primary home care attendants could not provide this level of care, generally, and the attendant would not provide services if Ms. C. was not in the home.

172. Ms. C. has also attempted to utilize home health aide services, allegedly available through MDCP. Ms. C. contacted approximately 30 Medicaid home health agencies in Austin; no agency was willing to provide a home health aide for Kaitlyn, either because it did not provide services to children or because the agency determined that Kaitlyn's needs exceeded the skill level of a home health aide.

173. Without the additional medically necessary nursing services she requires, Kaitlyn is at risk of being placed in an institution.

Aaron D.

174. Aaron Davidson is ten-years-old and lives with his maternal grandmother and guardian, Ms. D., in Hallsville, Texas.

175. Aaron has Ellis-Creveld Syndrome and Jeune Thoracic Dystrophy Syndrome. These syndromes manifest themselves in Aaron in a number of ways including: blockage of the respiratory system; cardiac problems; underlying reactive airway disease, resulting in

frequent serious infection; seizures; significant developmental delays; visual impairment; mobility impairment; sleep apnea; and, physical disabilities impacting the structure of his rib cage.

176. Aaron wears leg braces and is only able to walk short distances. He uses a wheelchair for long distances.

177. Aaron has a tracheotomy to assist his breathing. He requires daily nebulizer treatments and constant monitoring of his respiratory condition. Aaron's tracheotomy must be suctioned every fifteen to thirty minutes, twenty-four hours per day. Persons providing Aaron's care must exercise professional judgment in order to diagnose a respiratory emergency and administer nebulizer treatments and/or pediatric CPR using a tracheotomy.

178. Aaron also takes the medication, Theophylline. Theophylline must be administered at precise times because failure to give the medication on time can result in a severe reaction, including worsening of the respiratory condition if the dose is late, or increased heart rate and possible heart attack if the dose is given too early. Theophylline must be administered every 6 hours.

179. Aaron has limited ability to swallow; all medications and most of his nutrition is provided through a gastrostomy tube ("g-tube"). Aaron must be administered Albuterol four-to-six times per day. His other medications include: Zantac, Motrin, and Mylanta.

180. Aaron has a seizure disorder for which he cannot take medication because of the other medications he must take. When Aaron is having a seizure, he requires medical

monitoring, oxygen, and, if a nurse is not present, he must be taken to the hospital emergency room, sometimes by ambulance.

181. Aaron's physical disability impacts the structure of his rib cage and his respiratory system. It can be life threatening if Aaron is not correctly positioned, or if he should fall and injure his rib cage, because of his respiratory illness.

182. Aaron also requires monitoring of his g-tube and tracheotomy sites for skin breakdown and infection. He has some prolapse of his intestinal mucosae into his gastrostomy bag, for which he is being treated with silver nitrate.

183. Aaron's grandmother has numerous health problems of her own. She had surgery in July 1998, as a result of breast cancer. She also has genetically high cholesterol, which makes her very susceptible to stroke, and severe arthritis in her knees and hands resulting in physical limitations which make it difficult for her to provide all of Aaron's care. When the arthritis is active, she experiences a great deal of pain and cannot lift Aaron.

184. Additionally, a work-related back and neck injury limit Ms. D's ability to lift Aaron. Although she has been ordered by her doctor not to lift anything over ten pounds, she daily risks exacerbation of her injury because she must sometimes lift Aaron to care for him.

185. Ms. D. is not a nurse nor has she had formal medical training. Ms. D. is currently employed as a food service provider for the local school district. The lack of nursing care for Aaron makes it difficult for her to work. Because Aaron misses many days of school due to illness, Ms. D. has no recourse but to stay home with him, thus missing work, and losing pay.

186. On the days when Aaron does go to school, Ms. D. is usually called to the school at least once per day to handle a health problem for Aaron.

187. Aaron also needs to be monitored during the night. He must be suctioned, and he must be re-positioned in bed. When Ms. D. has no nursing care for Aaron at night, she sleeps with Aaron, and wakes every fifteen-to-thirty minutes to check on Aaron and provide suctioning. Aaron's apnea monitor usually goes off several times at night, and it is not unusual for him to require a tracheostomy tube change during the night.

188. When Aaron is sick, his apnea monitor goes off more often, he must be suctioned more often and, if he is in the wrong position at night, he stops breathing. Ms. D. has to be awake most of the night to suction him and rouse him when he stops breathing.

189. Aaron's primary care physician, Karen Roberts, M.D., recommends that Aaron receive at least 50 hours of nursing services per week.

190. Aaron became eligible for Medicaid when he was approximately six months old.

191. Aaron spent much of the first two years of his life in the hospital because of repeated occurrences of pneumonia and other infections.

192. Aaron began participating in the MDCP program on June 22, 1992.

193. MDCP provided Aaron with 20 hours of nursing services per week until January 1993.

194. From January 1993 until April 1994, MDCP provided Aaron with 24 hours of nursing services per week.

195. From April 1994 until August 1995, MDCP provided Aaron with 28 hours of nursing services per week.

196. Beginning in 1995, Texas Medicaid provided Aaron with 14 hours of nursing service per week through CCP and 28 hours of nursing services per week through MDCP.

197. In August 1995, MDCP reduced the number of nursing services hours from 28 to 26 hours per week; however, CCP increased the number of nursing services hours from 14 to 18.

198. Until June 1997, Texas Medicaid provided Aaron with 44 hours of nursing services per week; 18 hours were provided through CCP and 26 hours were provided through MDCP.

199. On June 27, 1997, Texas Medicaid, through NHIC, terminated the CCP nursing services being provided to Aaron.

200. Texas Medicaid, through NHIC, terminated the CCP nursing services without evaluation of Aaron, consultation with his physicians, and in direct contradiction to the recommendations of Aaron's treating physician and nurses.

201. Ms. D. requested a fair hearing to appeal Texas Medicaid's termination of CCP nursing services.

202. On October 20, 1997, the TDH hearing officer, John Garrett, issued a one paragraph decision upholding the decision of Texas Medicaid, stating that "the preponderance of the evidence reflects that there was no medical necessity for CCP skilled nursing intervention." The decision does not describe any of the "evidence;" it makes no

reference to Aaron's medical needs, nor does it refer to the opinion of Aaron's treating physician.

203. Because of changes to the administration of its program, in February 1998, MDCP proposed reducing Aaron's nursing services; however, MDCP agreed to continue providing Aaron with 26 hours of nursing services per week until July 1998, because of Ms. D's health status.

204. MDCP reduced Aaron's nursing services hours to 11.75 hours per week in July 1998.

205. Aaron's treating physician recommends that Aaron receive at least 50 hours of nursing services per week; however, Aaron is only receiving approximately 12 hours of nursing services per week through the MDCP program.

206. In June 1999, Aaron's physician and nursing services provider, Jordan Home Health, submitted a request for prior authorization to provide Aaron with 60 hours of nursing services per week for the period July 16, 1999 through October 15, 1999, through CCP.

207. Texas Medicaid denied this request. The notice of denial stated only that the "medical information received does not support medical necessity for the service(s) or therapy." It failed to provide any other information about the basis for the denial of nursing services, and the federal regulations cited were incorrect and do not support the denial of services.

208. Because of Texas Medicaid's denial of CCP nursing services and the changes to MDCP, Aaron is currently unable to access 38 hours of medically necessary nursing services per week, as prescribed by his treating physician.

209. Without the additional medically necessary nursing services he requires, Aaron is at risk of being placed in a nursing facility or other institution.

Andrew M.

210. Andrew M. is eleven-years-old and lives in Tyler, Texas, with his mother, Ms. M. Ms. M. works full-time, outside the home.

211. Andrew was diagnosed with microcephaly at birth. As a result of the microcephaly, Andrew has a seizure disorder and mental retardation. Andrew is unable to speak and is completely dependent upon his mother or other care-givers for feeding, bathing, transferring, and other daily activities. Andrew is able to eat by mouth but he must be fed pureed foods and monitored for choking, aspiration, and reflux. He requires incontinence care and ongoing implementation of a bowel program to prevent constipation and impaction.

212. Andrew also has a respiratory condition that requires nebulizer treatments and twice daily chest physiotherapy treatments ("CPT"). These treatments consist of percussing his chest and suctioning his airway. Andrew must be continuously monitored for respiratory complications, including upper respiratory infections and pneumonia.

213. Due to the seizure disorder, Andrew requires the administration of seizure medications several times per day. These medications have only limited effectiveness and

Andrew continues to have five to ten seizures every day. As a result, Andrew must be observed for seizures on an ongoing basis.

214. Andrew also requires continuous assessment of his vital signs for cardiac problems and hypothermia.

215. Andrew must be turned and positioned appropriately due to his right hip dysplasia and requires ongoing assessment for skin breakdown. He also has scoliosis and his left femur is beginning to show signs of dysplasia.

216. In 1992, Andrew became eligible for Medicaid when he began participating in the MDCP program. Initially, MDCP provided 8 hours per week of nursing services to Andrew. The number of hours of nursing services were gradually increased from 8 hours per week to 28 hours per week.

217. Andrew's pediatrician, Mark Barret. M. D., and the nursing services providers, Jordan Health Services, Inc. and Mother Frances Home Care, have consistently recommended that Andrew receive at least 60 hours of nursing services per week..

218. In September 1997, Texas Medicaid began providing Andrew with 40 hours per week of nursing services, through CCP.

219. Until March 1998, Texas Medicaid provided Andrew with 68 hours of nursing services per week; he was provided 40 hours per week of nursing services through CCP and 28 hours per week through the MDCP program.

220. On February 24, 1998, Texas Medicaid, through NHIC, sent Ms. M. notice that Andrew's 40 hours per week of CCP nursing services would be reduced each month by ten hours per week and that they would be terminated as of May 25, 1998.

221. Texas Medicaid, through NHIC, reduced and terminated the CCP nursing services, without evaluation of Andrew, consultation with his physicians, and in direct contradiction to the recommendations of Andrew's treating physician and nurses.

222. Andrew's treating physicians sent letters to Texas Medicaid, dated March 10, 1998, documenting Andrew's continued need for nursing services and requesting that it not terminate the CCP nursing services.

223. Additionally, Ms. M. requested a Medicaid fair hearing to appeal the reduction and impending termination of Andrew's CCP nursing services. Ms. M. did not proceed with the fair hearing, however, because TDH staff told her that the hearing would only address the reduction of nursing services through May 24, 1998, and that the hearing officer would not address Andrew's current need for nursing services. TDH staff told her that the treating physician and nursing agency would have to re-apply for prior authorization to provide nursing services after May 24, 1998, and that Ms. M. would have to request another hearing if those services were denied.

224. In June 1998, MDCP reduced Andrew's nursing services hours from 24 hours per week to 20 hours per week.

225. Texas Medicaid did not provide nursing services to Andrew through CCP again until June 1999.

226. In June1999, Andrew's treating physician and nursing services provider submitted a prior authorization request to Texas Medicaid to provide Andrew with 40 hours of nursing services per week, through CCP.

227. However, Texas Medicaid only approved 40 hours of nursing services per week for the period June 15, 1999 through July 14, 1999. For the period of July 15, 1999 through August 14, 1999, Texas Medicaid approved 30 hours of nursing services per week, and for the period of August 15, 1999 through September 15, 1999, it approved only 20 hours of nursing services per week.

228. Andrew continues to require 60 hours of nursing services per week; however, he only receives 20 hours per week of nursing services provided through MDCP and Texas Medicaid is in the process of reducing his nursing services to 20 hours per week, through CCP. Therefore, Andrew is unable to obtain 20 hours per week of medically necessary nursing services.

Evan W.

229. Evan W. is eleven-years-old and lives in Houston with his mother and father, Mr. and Mrs. W. Both of Evan's parents work outside the home.

230. At the age of three, Evan was diagnosed with Familial Dysautonomia, a rare hereditary disease that affects both autonomic and sensory nerve cells. These nerve cells control bodily functions such as sweating, swallowing, regulation of blood pressure and body temperature, and the ability to cry with tears; they are also responsible for pain, heat perception, and taste.

231. Familial Dysautonomia causes dysphagia and dysarthria which affect Evan's ability to swallow. Evan must ingest liquids through a gastrostomy tube ("g-tube"). Although, he can eat thin, soft foods by mouth, he requires close monitoring due to the likelihood of choking and aspiration.

232. Familial Dysautonomia also causes fluctuation in Evan's body temperature, requiring ongoing monitoring for hypothermia.

233. Familial Dysautonomia also inhibits Evan's ability to feel pain and he must be constantly observed to avoid injury. Evan has thoracic scoliosis and kyphosis and must wear a body brace. Because he is unable to feel pain, he requires ongoing assessment of his skin to avoid skin breakdown caused by the brace.

234. Evan also needs assistance with toileting, including the provision of incontinence care and a bowel program to prevent constipation and impaction.

235. The most significant feature of Familial Dysautonomia, however, is the unpredictable onset of "dysautonomic crisis." Dysautonomic crises are life threatening episodes that cause Evan's vital signs to radically fluctuate, including significant increases in his blood pressure and heart rate. During the past summer, Evan had a crisis every day due to hypothermia caused by air-conditioned room temperatures.

236. Diagnosis of a Familial Dysautonomia crisis requires the exercise of professional judgment to recognize the sometimes subtle signs of onset, including, retching, listlessness, or difficulty swallowing.

237. Immediate treatment required for a Familial Dysautonomia crisis includes the administration of the medications Valium and Catapres. The timely and proper administration of these medications, as well as implementation of an individualized protocol, can eliminate the need for treatment in an emergency room and subsequent hospitalization.

238. Felicia Axelrod, M.D., the United State's foremost expert in Familial Dysautonomia and one of Evan's treating physicians, has developed the following individualized protocol to be followed when Evan experiences a dysautonomic crisis:

(A) administer Valium and Catapres either rectally or through the g-tube;
(B) monitor Evan's blood pressure and other vital signs;
(C) administer an enema and re-administer Valium if no improvement in twenty (20) minutes;
(D) re-administer Valium and Catapres if no improvement after thirty (30) minutes;
(E) administer Pedialyte through the g-tube;
(F) reassess three hours after the last administration of Valium; if sweating or gagging, implement crisis protocol again. If "not quite himself," re-administer Valium.

239. Implementation of the protocol requires professional judgment to determine when and at what dosage the medicine should be administered. It also requires that the care giver be very familiar with Evan and the symptoms that indicate onset of crisis.

240. During 1998, Evan experienced an increased number of these unpredictable crises, ranging from one-to-three crises per week. On November 4, 1998, Evan experienced a dysautonomial crisis that required treatment in the emergency room.

241. Because of his difficulty eating and frequent Familial Dysautonomia crises, Evan has failed to gain weight within the last year and currently falls within the malnourished weight range. To address this problem, Evan must be provided Pediasure

supplement through his g-tube three times per day. The g-tube feedings take place two times during the day and he is provided a third feeding that lasts the entire night.

242. In 1992, Evan became eligible for Medicaid when he began participating in MDCP. Initially, MDCP provided Evan ten hours per week of nursing services. These services gradually increased to 20 hours per week during the first year of participation in MDCP. He continued to receive 20 hours per week of nursing services until May 1999.

243. In early 1997, Ms. W. was informed that due to changes in the array of services available from MDCP, Evan's nursing hours would be reduced to approximately seven hours of nursing services per week. Due to intervention by his local congressional representative, this reduction was not been implemented and Evan continued to receive approximately 20 hours per week of nursing services until May 1999.

244. According to Evan's treating physicians Drs. Axelrod and Sheena, Evan requires at least 40 hours of nursing services per week.

245. Due to the ongoing decrease of MDCP nursing services, Dr. Sheena and Evan's treating nurse, Natalie Mukherjee, submitted a request to Texas Medicaid for additional nursing services, through CCP, in June 1997.

246. Texas Medicaid, through NHIC, denied the request for nursing services, without evaluation of Evan, consultation with his physicians, and in direct contradiction to the recommendations of Evan's treating physician and nurses.

247. The notice of denial states that "the medical information received does not support approval." It failed to provide any other information about the basis for the denial

of nursing services, and it did not describe the federal regulations that support the denial of services.

248. Ms. W. appealed the denial of nursing services. A fair hearing was held on October 27, 1997, and the TDH hearing officer, Dan Meador, issued a decision on December 1, 1997. The hearing officer held that the nursing services had been properly denied, finding that "none of the care Evan needs requires a skilled nurse to provide it" and that "[t]he possibility of future medical crisis does not create a medical necessity for skilled nursing." The hearing officer did not make any findings with regard to the documentation of medical necessity provided by Evan's treating physicians and care providers. The hearing officer simply affirmed Texas Medicaid's decision and did not defer to, or even mention, the opinions of Evan's treating physician and nurses.

249. In February 1998, Dr. Sheena and Evan's treating nursing agency, Denson Community Health, again requested that Texas Medicaid provide 20 hours per week of nursing services for Evan, through CCP. Texas Medicaid again denied the request.

250. The notice of denial stated that the "medical information received does not support approval." The notice provided no other information about the basis of the denial, and it did not include the specific federal regulations that support the denial.

251. In December 1998, Texas Medicaid approved 20 hours per week of nursing services on a temporary basis due to Evan's malnourished status; at this time, he continues to receive 20 hours per week of nursing services through CCP.

252. MDCP reduced Evan's nursing services to between ten and 15 hours per week in May 1999.

253. Evan continues to require 40 hours per week of nursing services; however he is only able to access between 30 and 35 hours per week through CCP and MDCP.

254. Without the additional medically necessary nursing services he requires, Evan is at risk of being placed in a nursing facility or other institution.

VII. FIRST CAUSE OF ACTION - THE MEDICAID ACT

255. Defendants, by their actions and inactions set forth above, violate provisions of the Medicaid Act, 42 U.S.C. § 1396 *et seq*., and its implementing regulations by:

(a) failing to inform Plaintiffs of the scope of services available under the EPSDT benefit of the Medicaid program, in violation of 42 U.S.C. § 1396(a)(43)(A);

(b) denying Plaintiffs all medically necessary services they are entitled to, in violation of 42 U.S.C. § 1396d(r)(5);

(c) failing to set reasonable standards in the operation of the EPSDT program, in violation of 42 U.S.C. § 1396a(a)(17);

(d) failing to provide EPSDT services in a sufficient amount, duration and scope to reasonably achieve their purpose, in violation of 42 C.F.R. § 440.230(b);

(e) arbitrarily denying and reducing EPSDT services in amount, duration and scope because of the diagnosis, type of illness or condition of Plaintiffs, in violation of 42 C.F.R. §§ 440.230(b) and (c);

(f) failing to provide written notice and the opportunity to request a fair hearing to Plaintiffs whose claim for services were denied, reduced or terminated, or not acted upon with reasonable promptness, in violation of 42 U.S.C. § 1396a(a)(3) and. 42 C.F.R. § 431.200 *et seq*.; and,

(g) failing to provide written notice that includes: a statement of what action Texas Medicaid intends to take; the reasons for the intended action; the specific regulations that support, or the change in Federal or State law that require the action; an explanation of the individual's right to request an evidentiary hearing if one is available, or a State agency hearing; in cases of an action based on a change in law, the circumstances under which a hearing will be granted; and, an explanation of the circumstances under which Medicaid is continued if a hearing is requested, in violation of 42 C.F.R. § 431.210.

VIII. SECOND CAUSE OF ACTION - THE AMERICANS WITH DISABILITIES ACT

256. Defendants, by their actions and inactions set forth above, violate the Americans with Disabilities Act, 42 U.S.C. § 12131 *et seq*. and implementing regulations at 28 C.F.R. Part 35 by:

(a) denying, on the basis of the severity and type of disability, the opportunity to benefit from Defendants' services and programs, as prohibited by 28 C.F.R. § 35.130(b)(1)(I); and,

(b) requiring Plaintiffs to seek institutional placement in order to obtain all medically necessary services and thereby failing to administer Defendants' services, programs, and

activities in the most integrated setting appropriate to the needs of Plaintiffs, in violation of 28 C.F.R. § 35.130(d).

IX. THIRD CAUSE OF ACTION — DUE PROCESS CLAUSE OF THE FOURTEENTH AMENDMENT TO THE UNITED STATES CONSTITUTION

257. Defendants, by their actions and inactions set forth above, deprive Plaintiffs of their entitlement to Medicaid services without due process of law, in violation of the Fourteenth Amendment to the United States Constitution and 42 U.S.C. § 1983, by failing to provide written notice and the opportunity to request a fair hearing to Plaintiffs whose claim for services were denied, reduced or terminated, or not acted upon with reasonable promptness.

X. PRAYER FOR RELIEF

WHEREFORE, Plaintiffs respectfully request that this Court:

1. assume jurisdiction of this action;
2. certify that this action may proceed as a class action on behalf of all Medicaid eligible individuals under the age of twenty-one in Texas who have been, or will be, unlawfully denied medically necessary services;
3. declare that Defendants' actions and inactions violate the Medicaid Act, the Americans with Disabilities Act, and the Fourteenth Amendment to the United States Constitution;
4. issue preliminary and permanent injunctive relief enjoining Defendants from violating these laws and requiring Defendants to immediately provide all medically necessary services to which Plaintiffs are entitled under the Medicaid program; and,

5. issue such other relief as may be just, equitable and appropriate, including an award of reasonable attorneys' fees, litigation expenses, and costs.

Dated: August 6, 1999

Respectfully submitted,

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